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Sexuality and Disability: Some Contributions of a Socio-Representational Approach

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Our article aims to highlight how the association between disability(s) and sexuality(s) reveals major psychosocial issues. In this context, the study of social representations offers a heuristic way of questioning certain foundations of our judgments, by revealing their social background and explanatory effectiveness. Disability and sexuality are quasi-prototypical objects for the study of these phenomena because these social objects incorporate multiple and dynamic socio-symbolic issues. This paper aims to contribute to and define a new area of social science inquiry to which social representations theory can contribute. We explore ‘normal sexuality’ and ‘disabled sexuality’ to present some representational content and their implications using data from the literature, together with a selection of empirical illustrations. Taking into account the normative and socio-cultural context makes it possible to highlight the role of social representations, which often serve as justifying theories in the construction of social norms and rules in matters of sexuality, both for ‘normal’ sexuality and ‘disabled sexuality’.

Keywords: sexuality, disability, social representations

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Our paper aims to highlight the encounter between disability and sexuality as a revelation of major psychosocial issues. Through this contribution we wish to question some of the foundations of our judgements by showing their social inscription and their explanatory effectiveness. These judgements take shape and meaning when we are led to evaluate or explain a whole set of facts or social phenomena. They allow us to explain the world and to construct ‘regimes of truths’ for everyday explanation. Disability and sexuality are quasi-prototypical objects for the study of these phenomena. By taking into account the normative and socio-cultural context, we can highlight the role of social representations, which often serve as theories of justification for the construction of social norms and rules in the area of sexuality, whether it be ‘normal’ or ‘disabled’. These social theories of common sense constitute a ‘foundation’ on which individuals and societies rely to make sense of situations, while outlining related social practices and their legitimacy. This paper aims to open and foster a ‘new’ area of interest and inquiry within social representations theory, and to contribute with this critical lens to already existing research within social psychology and other social sciences devoted to sexuality in disability and to disabilities. Some of the elements used to illustrate our reflection will refer to particular national contexts, as the proposed reflections were produced by a Franco-Brazilian working group.

The study of social representations (cf. Abric, 1994; Jodelet, 1989; Moscovici, 1961) seems to us to be a heuristic way of responding to the challenges of exploring the meaning (content) and internal logics of these social objects. The articulation of two fundamental dimensions of representation – representation-as-content and representation-as-process (cf. Abric, 1987; Dany, 2019a) – testifies to the dual nature of representation as constituent thought and constituted thought, a general characteristic that affects the processing of information and knowledge of social objects. Disability as sexuality constitutes sensitive, socially marked objects. They can be apprehended as 'hot' social objects that produce multiple and dynamic interactions between the individual and the collective. The representational thinking constitutes an heuristic way to explore social objects, as disability and sexuality, that be in the heart of social stakes (communication, social relations, identity, ideology, social norms).

First, we will approach disability from a psychosocial perspective in order to highlight the dual material and symbolic determination of the situation of disabled people. We will then discuss normal sexuality and disabled sexuality in order to present some representational content and its implications, with the help of data from the literature, together with empirical illustrations resulting from the work of the research team mentioned above, aimed at exemplifying the highlighted phenomena.

DISABILITY FROM A PSYCHOSOCIAL PERSPECTIVE

As highlighted by the World Health Organization within the framework of the International Classification of Diseases (World Health Organization [WHO], 2011), disability refers to difficulties encountered in one of the following three functional domains: (a) impairments (alterations in organic functions or anatomical structures), (b) activity limitations (difficulties a person may encounter in an activity), and (c) participation restrictions, which refer to the problems an individual may encounter in participating in a life situation. These functional domains are closely linked to all the environmental and personal factors that may interact with them. Taking this perspective into account has led to the emergence of the term ‘person in a situation of disability’, which is now widely used and is tending to replace the term ‘disabled person’. This terminology emphasizes the fact that while conditions cause impairments and disabilities, it is the barriers or facilitators (e.g., material, legislative and technological environments) encountered that enable individuals to fully participate socially (cf. Fougeyrollas, 1997). Furthermore, it helps to avoid objectifying people by referring to them as ‘disabled’. Beyond this general classification, legal definitions of disability can be found in different countries. As an illustration, the definitions of disability in the French and Brazilian contexts show clear similarities. For example, both definitions included limitations or restriction to active participation in life in society, suffered in their environment by a person due to a substantial, lasting or definitive alteration of one or several physical, sensory, mental, cognitive or psychic functions, multiple disability or an incapacitating health condition. Persons with disabilities are considered at those who have long-term physical, intellectual or sensory impairments which, in interaction with various barriers, may obstruct their full and effective participation in society on an equal basis with others.

A fundamental element that emerges from the analysis of these definitions concerns the impact of conditions on the ability of people with disabilities to participate in society. Thus, from a psychosocial point of view, disability can be analyzed as a general interpretative framework within which issues relating to the conditions of participation of individuals in the social world can be understood. From this perspective, the situation of disability ‘assigns’ a social place to individuals and gives full meaning to the social dimension of health. Social health “concerns the joint consideration of the two structural and structuring elements that are social inscription (e.g., roles, status, social expectations, …) and social participation (e.g., interactions and personal relationships, knowledge, communication, social capacity and possibility, ...)” (Dany, 2019b, p. 181).

The *social place* of people with disabilities – an amalgam of their social inscription and participation – is the basis on which social practices and representations are developed, legitimized and given meaning. The notion of social place leads us to consider the place of the ‘disabled’ in a wider social field that categorizes, classifies and structures groups and produces ‘communities of conditions’ (Apostolidis & Dany, 2014). This perspective is fundamental because it requires us to bear in mind that the conditions of access to social participation are not strictly based on ‘objective’ modalities. In other words, the material conditions that would make it possible to guarantee this participation (e.g., the right to be integrated or accommodated within companies or schools, assistance with physical access to places, participation in representative or deliberative bodies in the social and health fields, etc.).

The environment is socio-cultural; and it is the representations that dictate the laws, rights and duties towards minorities, such as the disabled. Based on this observation, if we modify the representations, we help to adapt the environment and we can reduce the disability. This perspective can be found in Denise Jodelet's (1996) analysis of exclusion. The inclusion and exclusion of this or that individual or group from society is defined in relation to a material, but also a symbolic, determination. Social exclusion, as a psychosocial phenomenon, always implies a specific organization of interpersonal relations and social relationships. Thinking about the issue of exclusion (or its opposite, integration), refers us to the way in which this organization of exclusion takes shape in a regime of social organization (Apostolidis & Dany, 2014).

Exclusion is not a state that some possess, others do not. There is no exclusion as opposed to inclusion. Both are part of the same process and constitute the modern face of the process of exploitation and domination. The excluded are not on the margin of society, they participate in it, and what is more, they replenish and sustain it, but they suffer a lot, because they are included even through humiliation and the denial of humanity, even if they share social rights on a legal level (Sawaia, 2000)

This question of social participation is central to the analysis of the psychosocial situation of people with disabilities. How can society propose a project that aims to develop this participation? How can it promote inclusion or build what we call ‘an inclusive society’? What are the limits that society can set for itself in its project, or even its ‘desire’ to include people with disabilities? To go further, and in connection with our subject, can access to sexuality or the expression of the affective and sexual life of people with disabilities be understood as objectives to be guaranteed, supported or even promoted in a societal project with an inclusive aim?

These different questions point to the particularly conflicting dimension that ‘disabled sexuality’ poses to the societal project of social participation and the inclusion of disabled people. This conflict is based, for example, on the limit that can be underlined regarding the need to distinguish between the public and private spheres (sexuality being part of the private and intimate sphere). Moreover, sexuality is a ‘separate’ human activity and is subject to particularly strong normative issues in all societies. Concern for the sexuality of people with disabilities thus transcends the project of emancipation and the inclusion of such persons, and replaces it with ideological issues coloured by social values.

SEXUALITY WITHIN THE PRISM OF REPRESENTATIONS

‘Normal’ Sexuality[1]

Sexuality refers to a central dimension of the human species that includes sex, gender, sexual orientation, eroticism, emotional attachment (feelings of love) and reproduction. It is a multidimensional concept that relates to the experience or expression of thoughts, fantasies, desires, behaviours, attitudes, values, activities, practices, roles and relationships. Sexual experiences include both sexual thoughts (fantasies or erotic dreams) and sensual kissing, masturbation (alone or with a partner), sexual fondling and play, oral sex, vaginal penetration and anal intercourse (Rosen et al., 1993). Sexuality is the result of “complex interactions between the physiological, the cognitive, the emotional, the behavioural, the relational and the sociocultural as opposed to the predominant influence of the biological and psychological components” (Bergeron et al., 2008).

Beyond these definitions, we must take into account the fact that intimate and sexual life, in general, involves fundamental questions both for the individual and for society (Foucault, 1976). Sexuality and intimacy are ‘private’ and ‘public’ objects, which activate normative issues of rare salience. However, the existence of a standard implies the attribution of a value recognized by the collective. In other words, the norms related to sexuality – whether in the thought and/or the act – tell us about the values promoted within a given society. As Bozon and Leridon (1993) underline: “social relations and social control are not at the periphery of the sexual, but at the very heart of practices and their meaning” (1993, p. 1178). These values

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[1] The qualifier ‘normal’ does not represent a value judgment concerning what a ‘normal’ versus ‘abnormal’ sexuality would really be. The systematic use of quotation marks also aims to underline the constructed character of the terms and their potential in terms of categorizing events, facts and people.

find their origin in the socio-cultural heritage of societies; they translate visions of the world and constitute, in this sense, places of expression of social representations.

Furthermore, there is a social representation of the normal content of the sexual act. This ‘normal’ sexuality draws the outlines of what is expected, and, by extension, of what is ‘good’. The social representation of the ‘normal’ content of the sexual act includes penetration, leading to orgasm for both partners at the same time and involving two people of the opposite sex (Spencer, 1993). The penetrative norm is so ‘obvious’ that it is difficult for individuals questioned about sexual practices to characterize the sexual act without making reference to it (cf. Bajos et al., 2008). In addition, in some studies, the representations of sexuality are limited to sexual intercourse between two people of the opposite sex (Macedo et al., 2013; Nery et al., 2011). In this manner, representations express the dominant social order by maintaining the social institution of heterosexuality (Diamond, 2005).

We can also observe that a cleavage between an *affective-conjugal* female sexuality and an *instinctual and individual* male sexuality persists despite societal changes (Bajos et al., 2008, p. 565). For example, in France, 73% of women and 59% of men adhere to the idea that “by nature, men have more sexual needs than women” (Bajos et al., 2008, p. 547). These representations of female versus male sexuality outline the ‘acceptable’ from a normative point of view. The injunction or the sexual duty is also significant for individuals, through the prism of balance or quality of life. Thus, 30.9% of French women and 42.8% of French people consider sexuality to be ‘essential’ and 54.4% and 48.5% respectively consider it ‘important’ (Bajos et al., 2008). This question of balance or the quality of sexual life echoes the ‘ground movement’ that saw sexuality become the founding experience of marital and emotional relationships (Bajos & Bozon, 2008). The inclusion of sexuality as the basis and engine of relationships has been accompanied by new expectations of it, such as the recognition of the right to a fulfilling sex life. These social changes are now accompanied by a medicalization of sexuality that reflects new social expectations with regards to it, such as the maintenance or development of a sexual life of quality (Giami, 2004).

This context echoes the development and legitimization of the notion of sexual health by the World Health Organization (WHO). Sexual health is a state of physical, mental and social well-being in the area of sexuality. It requires a positive and respectful approach to sexuality and sexual relations, as well as the possibility of having sexual experiences that are sources of pleasure and without risk, free from any coercion, discrimination or violence. One of the criticisms that can be made of this definition is similar to that produced for the positive definition of health, namely the fact that when we identify health (and therefore sexuality) with well-being, we go beyond a strict definition. Scientific, social and moral norms are *de facto* introduced to elaborate this definition and these norms have the characteristic of being relative (cf. Boorse, 1977; Simard, 2018). The development of the concept of sexual health has a strong implication at the societal level, that of the responsibility of our societies in maintaining or providing access to good or bad sexual health (Gardien, 2012). The corollary of this social responsibility is to take sexuality out of the strict domain of intimacy and to add a social dimension to it, which raises the question of social justice (Gardien, 2012).

Another element concerns what comes under the semiology of romantic discourse in connection with sexuality. To be more precise, there is a strong tendency (at the normative and representational levels) to link feeling and sexuality (e.g., Apostolidis, 2000; Apostolidis & Deschamps, 2003; Queiroz et al., 2015). From this perspective, the feeling of love would be an ‘indispensable’ prerequisite for the sexual act; the sexual act without love or feeling would in fact deviate from the norm. As Christiaens (1983) underlines, in his analysis of sexuality in relation to situations of disability: “Love was introduced as the most important ethical criterion, well beyond sexuality and fertility themselves: sex is good if it symbolizes the transmission of love” (1985, p. 189). The following extracts from Opinion 118 on the Emotional and Sexual Life of Persons with Disabilities – the question of sexual assistance of the National Consultative Ethics Committee (CCNE) are relatively illustrative of the ‘social promotion’ of the link between love and sexuality.

> “Sexuality cannot be talked about without emphasizing the importance of emotional bonding and romantic relationships.” (Comité Consultatif National d'Ethique [CCNE], 2012, p. 4)
>
> “We can wish everyone the possibility of a romantic encounter based on emotions, feelings and moral commitments.” (Comité Consultatif National d'Ethique [CCNE], 2012, p. 12)

This social promotion of love in sexuality is however subject to discussion, as shown by studies conducted on the general population in the French context. A survey on the context of sexuality in France, carried out in 2006 among nearly 12,000 French people, can enlighten us (cf. Bajos & Bozon, 2008). In an analysis of the typologies of groups and the characteristics of sexual behaviour that distinguish them, the researchers were able to outline the characteristics of these groups. The idea was to show the possible diversity of relationships to sexuality, based on a set of characteristics (sexual behavioural traits). The typologies extracted from the analysis show the profiles of different individuals in the articulation they make between sexuality, relationships and feelings. While for some, sexuality is consubstantial with the couple and the feeling of love, for others, we can observe that this is not the case. All configurations are possible between these different elements of emotional and sexual life. The few elements that we have presented outline the socio-representational and normative components of sexuality. They bear witness to the fact that 'represented' sexuality articulates two ontologically different dimensions (nature vs. culture) which come together in social thought.

This perspective makes it possible to underline the fact that questions linked to 'private standards' or to the dimension of privacy are illuminated by their socio-cultural roots. Sexuality as a representation explains simultaneously the individual experience of individuals as social relationships, and of the normative, ideological and cultural permeation of what is considered to be personal. As Barillet-Lepley (2001) underlines, the issue linked to sexuality is at the same time one of social control and of intimate, collective and private experience. An essential difficulty will therefore arise from the management of social representations associated with sexuality.

'Disabled Sexuality'

At first glance, nothing suggests that disability would induce a separate sexuality, a sexuality that is ontologically different from the rest of the population, from that of the so-called 'normal'. We use the terminology of 'disabled sexualities' to link the definition of sexuality in the context of situations of disability to a specific or autonomous, or even exclusive, object of other modalities of sexuality. In other words, sexuality, through this terminology, does not refer to a sexuality which would have the characteristics of disability. In other words, we speak of 'disabled sexuality' to define the fact that these sexualities are influenced by the conditions (of any kind) produced by the disability situation. The terminology 'disabled sexuality' aims, in fact, to construct a problem object and to institute it as a relatively autonomous psychosocial object in order to identify the situational, organizational or societal issues that are specific to it. Disability can thus be analysed as a general interpretative framework in which the representations of sexuality (their impacts on the governance of bodies, on the management of public and private spaces), inform the conditions of social participation in the sexuality of individuals with disabilities.

First of all, we can inquire about the socio-sexual characteristics of people with disabilities. It is clear that data for assessing these practices are scarce. As part of the Disability, Incapacity and Dependence study carried out in France, we learn, for example, that with the exception of women aged 18-29, people declaring at least one disability living in ordinary homes are always less likely to have a socio-sexual relationship – that is to say, to be in a couple relationship or have a partner – than the general population (Centre Technique National d'Etudes et de Recherches sur les Handicaps et les Inadaptations [CTNERHI], 2004). In addition, people with disabilities living in institutions have fewer socio-sexual relationships than those living at home or than people without disabilities. The three socio-sexual modalities, which represent different degrees of involvement with a partner (marriage, a couple relationship, a sexual partnership), thus appear less frequently in individuals living in institutions (Giami & de Colomby, 2008).

A recent element of the debate on access to sexuality for people with disabilities relates (particularly in France) to the question of the right to sexuality. This right to sexuality is not a fundamental right because sexuality remains as an expression of freedom (cf. Deffains & Py, 2011; Nuss, 2008). In France, this right is not denied, but the specific nature of situations of dependency has a direct impact on the exercise of this right. Insofar as sexuality is a meaningful activity, we must ask ourselves whether people in a situation of dependence have a real possibility – and not only a formal one – of accessing or implementing it (cf. Gardien, 2012). As such, the analysis of the living conditions of people with disabilities highlights the obstacles and limits – due to their dependence – which they face in exercising their right to sexuality (Dany & Di Tucci, 2019). The impact of these obstacles and limitations is exacerbated by representations of ‘normal’ sexuality (e.g., orgasm, quality of sexual life). If normal sexuality is seen as a goal or a standard to be achieved, then people with disabilities who fail to complete the cycle of sexual responses are characterized as having a disorder (Tepper, 2000).

The normative dimension of sexuality, which provides the framework for what is desirable or expected in terms of sexuality, emphasizes the fact that the limitation on access to sexuality should not be considered solely on the level of disabilities or physical barriers. We must add to this characteristic an attitudinal characteristic relating to social thought (cf. McDonald et al., 2007; Maia & Ribeiro, 2010). Although relationships of dependence have a very direct impact on capabilities in terms of socio-sexual life, disabled people are also constrained by standards, values, representations, system, organization, means made available and social practices (Gardien, 2012). But what about these representations? A stubborn myth that can be found in different national contexts is that people with disabilities are asexual, have no sexual desire, interests, practices or needs, which leads to an infantilization of this social group (Giami et al., 1983; Maia & Ribeiro, 2010; Nuss, 2014).

Concomitantly with this asexual representation of the disabled person, we find another representation – especially concerning people with intellectual disabilities – in which people with disabilities are hypersexualised, as beings with uncontrollable and exacerbated desires: an animal or bestial sexuality (cf. Giami et al., 1983; Huet, 2017). The consideration of the sexuality of the mentally handicapped adult as a deviance, a 'bestiality', a 'perversion', illustrates a fundamental aspect of the symbolism on which the social distinction between 'normal' sexuality and 'disabled' sexuality is based (Apostolidis & Dany, 2014; Huet, 2017). The appropriation of these myths and representations by health professionals could have some consequences: limited access to information about sexuality; lack of training for health professionals; and limited access to prevention and health checks. In addition, people with disabilities are also more susceptible to infection by sexually transmitted infections such as HIV, or to suffering sexual abuse compared to someone from the general population (e.g., Delville & Mercier, 1997; Agence des Droits Fondamentaux de l'Union Européenne, 2014; Turk & Brown, 1993).

It is by taking all of these elements into account that the experience of the sexuality of people with disabilities can be considered as an experience of oppression, vulnerability or discrimination (Gesser & Nuernberg, 2014). This is based, in part, on representations which give form and meaning to 'disabled sexuality' (Apostolidis & Dany, 2014). Finally, it should be noted that the emotional and sexual life of people with intellectual disabilities undoubtedly present specificities linked to the forms of expression that these can take (more significant deviation from the norm), and to relational and social contexts (vulnerability, consent) in which sexuality is exercised (cf. Apostolidis & Dany, 2014; Barillet-Lepley, 2001; Campagna, 2012; Dany & Di Tucci, 2019; Giami et al., 1983; Vaginay, 2014). Even more than in the case of physical disability, the sexuality of people with mental disabilities crystallizes around notions of deviance (cf. Becker, 1985), abnormality, unthinkable reality or danger for the person themselves and/or for others.

EMPIRICAL ILLUSTRATIONS

The selection of empirical contributions is based on two main selection criteria. The first illustration aims to highlight the general characteristics associated with representations of 'disabled sexuality' in a context of mixed conjugality (disabled person, non-disabled person). In addition, it illustrates the impact of disability on the socio-affective relationship. The second illustration aims to highlight the role of representations in the apprehension of the sexual behaviours of disabled people (with brain injury, in our example), and more precisely the way in which the so-called ‘normal’ sexuality constitutes a general interpretative framework for thinking about ‘deviant’ sexualities.

Representations of ‘disabled sexuality’

The first empirical illustration refers to academic work that aimed to study representations of sexuality in the context of disability (Dany et al., 2019). The general research questions were: what are the social representations of the sexuality of the disabled person? And how do they take on meaning with reference to ‘normal’ sexuality? We used focus groups (*n* = 6; 42 subjects), carried out with psychology students (42 subjects divided into 2 groups of women, 2 groups of men and 2 mixed groups). Several methods were used in conducting the focus groups: (1) free association tasks (cf. Dany et al., 2015) produced individually and commented on/discussed in group; and (2) vignettes with photo of couples’ (a) physical disability and (b) mental disability, which were presented and discussed collectively. The focus groups were the subject of a thematic content analysis (Dany, 2016). We will briefly present two aspects of the results: the representational dimensions of ‘disabled sexuality’ and the implication of representations for viewing the couples’ relationship.

When we asked participants to imagine, to think about the sexuality of people with disabilities, they collectively tried to define, from their own knowledge and experiences, a representation of what ‘disabled sexuality’ is. In the analysis, we found several sub-themes that participate in this attempt to define this object – which for some, until then, had never been the subject of particular questioning (see Table 1). First, the participants talked about the difference between disabilities (mental and physical). The mental disability generated questions vis-à-vis the consent of the person, their conscience, their unpredictability (psychic and behavioural) and communication difficulties. Physical disability was associated more with the possibility of using one's sexuality. That is, physical disability was seen as posing problems in terms of sensations, pleasure and the achievement of penetrating sexuality. There was also a reference to the gender dimension of this sexuality. While women with disabilities were viewed through the weakness of their condition, men with disabilities were viewed through the weakness of their virility. Disabled sexuality was considered as incomplete sexuality which does not allow full satisfaction to be obtained. All these elements lead us to think of this sexuality as an *adaptive sexuality*, because of its deficient character. Thus, the idea here is that the couple, the partner and the sexuality must all adapt to the disability of the person.

Table 1.

Representational dimensions of 'disabled sexuality' (themes and illustrations)

A deficient sexuality		
Mental	Physical	Unsatisfying sexuality
- You don't know if she is lucid - That's right - Maybe she is in her world and she doesn't even realize that she is really in a relationship with her boyfriend and ... - Yes, because both for her and for him, Sylvain, it is a tree, it is a stone it is ... it is a magic stone, I do not know what I am saying, maybe I am extrapolating the thing.	- I said that this sexuality can be "complex", also because in some cases ... there can be erectile problems for men ... There can be motor problems that can impede sexuality	- Maybe they adopted different lifestyles from ours, maybe I don't know whether Marcel's companion (disabled man) will maybe look elsewhere for sexual partners, I don't know I imagine that finally ... she will perhaps satisfy her desires elsewhere than with her partner and always be with Marcel, and Marcel has an open mind because he understands that ...
Awareness (thinking about your sexuality)	*Possibility of acting on one's sexuality* *Gender aspect (virility vs fragility)*	*Incomplete sexuality*
←	***Adaptation***	→

Note: This table presents the three representational dimensions resulting from the content analysis of the focus groups. Each dimension is illustrated by an example of verbatims. The elements in italics following the focus group excerpts are the analytical categories resulting from the analysis of the representational dimensions. They allow us to highlight the central dimension (adaptation) resulting from the analysis.

When participants spoke about 'disabled sexuality' they also talked about the couple, conjugality and emotional life (Table 2). The participants in the focus groups defined an 'other', a particular conjugality affected by disability. This 'disabled conjugality' is characterized by the fact that the disability acts as a burden on the couple, and that it generates a dependence of the disabled person on the non-disabled person. This *altered conjugality* led participants to question themselves and to question the raison d'être of the couple. The marital relationship was seen as sacrificial for non-disabled spouses – a relationship generating dependency, with dissatisfaction shared by both spouses. The relationship was also seen as inauthentic, in the sense that participants questioned the motivation of non-disabled spouses to enter into this type of relationship. Finally, the participants mentioned the possible (or even necessary) compensation that the non-disabled spouse should or could implement to compensate for the deterioration of sexual relations (see Table 1).

Table 2.

Implication of representations for the couple relationship (themes and illustrations)

	Couple relationship	
A sacrificial relationship	Inauthenticity	Compensation
- Living with a disabled person, where in my daily life I think it is not necessarily easy, easy every day. So uh ... No, frankly, it takes a lot of courage and I think there must be a lot of love between the two because it's not easy every day ...	- Cerebral. And ... and I will tell you what I think sometimes, when I see this kind of thing, I say that there are two solutions: either the woman is really very passionate about him, or he must be really rich. You understand?	-So ... yes, it is true that after ... it is still quite complicated even in terms of fidelity, because a person we accept ... for ... for his wife ... even a woman feels sexual need and suddenly ... So if the husband can't meet your expectations afterwards, despite being his wife, sooner or later, I think there are impulses and how will she manage to deal with it? ... well, because it's complicated ...
Daily dependency and emotion *Shared dissatisfaction*	*Disability as a break from expected normality*	*An emotional relationship to compensate*
←	***Altered conjugality***	→

Note: This table presents the three representational dimensions resulting from the content analysis of the focus groups. Each dimension is illustrated by an example of verbatims. The elements in italics following the focus group excerpts are the analytical categories resulting from the analysis of the representational dimensions. They allow us to highlight the central dimension (altered conjugality) resulting from the analysis.

According to the results issued from the focus groups, the mixed couple (disabled person *versus* non-disabled person) question the normed couple (Vaginay, 2015). The normed couple contrary to the mixed-couple does not provoke, does not arouse a particular questioning of its ‘composition’ due to a perceived imbalance. In this context of a ‘different’ couple, the perception of the ‘normal’ spouse is situated on a continuum ranging from a narcissistic valorisation (the non-disabled spouse as an admirable person who sacrifices themselves) to a moral hold (the figure of the spouse who benefits from their disabled spouse). In a way, the perception of an imbalance leads observers to redefine the couple and “demands from the observer the existence of a hidden compensation” (Vaginay, 2015, p. 121).

Social Representations of the Sexuality of Brain-Injured People

Let us take another example resulting from research work (Huet, 2017) carried out amongst caregivers working with people with brain injuries. One axis of this work aimed to study the representations of the sexuality of people with cerebral lesions among caregivers via a focus group. The method used was based on the use of vignettes presenting professional situations relating to the management of patients’ sexuality. The study sample consisted of 21 caregivers, all women, divided into 4 groups.

The thematic analysis (cf. Smith, 1995) of the speeches revealed a meta-theme relating to the healthy vs. unhealthy sexual situations and behaviours encountered in brain-injured people. This classification follows social norms surrounding the expression of sexuality, and calls for professional practices aimed at protecting professional caregivers from symbolic pollution (cf. Douglas, 1966). According to this categorization, healthy sexuality is sexuality comprising the following characteristics: heterosexuality, single partner, affectionate/loving, non-caring relationship, partner of similar age, official (known) relationship, and mutual consent. Unhealthy sexuality has the following characteristics: multiple partners, homosexuality, prostitution, perversion, sex with a caregiver, significant age gap, violence and lack of consent. The following excerpt illustrates the co-construction of the discourse of caregivers concerning the sexuality of people with brain injuries (Figure 1).

Figure 1.

Characteristics associated with normal sexuality in the context of caring for people with cerebral lesions – Extract from a focus group (Huet, 2017)

- If they are just in their room, I leave them [man and woman with cerebral lesions]. - Frankly if they have no medical condition (...) If they have no need for protection and they are consenting. They can have feelings anyway, eh. - Yes, but with one person, not with everyone. - Oh no, with several people no. But with one person, if it's a relationship, they're not spreading germs or whatever and they're consenting, yeah. If it's with the entire patient group no, that means she's doing whatever (…) - If we have known them for months, if we see that they have an attachment. Being brain injured does not prevent them having feelings … If we see that there is an attachment, that they are often together… Now if we see that the person is changing. ... - They can fall in love.	• Heterosexuality • Stable couple • Official relationship • Affection • Respect and dignity • Consent • Private place, privacy • Outside of the care relationship

Note: On the left side of the table is an excerpt from focus groups in which participants talk about the 'normal' sexuality of brain-injured patients. On the right we find the characteristics of this 'normal' sexuality.

The caregivers spoke about the sexuality of the brain-injured person differently depending on whether they were talking about or describing the sexuality of men or women with a brain injury. The focus group analysis showed, for example, that men's sexuality is dominated by the presence of a sexual need and by genital sexuality. Caregivers perceived sexuality as ‘vital’ for brain-injured men, particularly genital sexual activity. The remarks of the caregivers suggest that male identity depends in part on the good functionality of their genitals (erection, ejaculation). In addition, caregivers distinguished two categories of men based on non-verbal information and the context that accompanies sexual behaviour. The first category is the ‘perverted’ man. This is defined by advanced age; unhealthy bodily expressions, such as a look or a smile; intentionality; awareness of sexual behaviour; and the inappropriate aspect of the situation (i.e., presence of the caregiver, time dedicated to care). The second category of brain-injured man is the ‘innocent’. His gaze is harmless, his behaviour involving the caregiver is aimed at discovery. The caregiver engages with their behaviour from a maternal point of view. There is no supposed unhealthy intentionality in their sexual behaviour, or else it is desexualized by caregivers. In the following excerpt, the caregivers in a focus group explain the difference between the perverse man and the innocent man, by equating the latter with a child (see Figure 2).

Figure 2.

The two sexual types of brain-injured men: The pervert and the innocent (Huet, 2017)

- It was not like an old pervert (...) it was more like childish exploration.
- Yeah, a little innocent.
- So we weren't like, disgusted, like we weren't yelling at him like he was a 40-year-old guy and we could that see in his eyes… Because we can sometimes see in their eyes that it's perverse, or that ... There, it was a look ...
- It was innocent.
- (...) it felt more maternal... I don't know, it didn’t feel unhealthy...
- Reassured.
- That’s it! Because we’re women, we’re curvy. I think it reassured the boy. In the shower, he was like this, "you're beautiful! ". He was trying to touch our curves, but it wasn’t the sort of… There you go. [the participant asks others who nod] (…)
- They [the perverts] do it on purpose?
- [several participants at the same time] Yes.

Note: On the left side of the table is an excerpt from focus groups in which participants talk about the 'normal' sexuality of brain-injured patients. On the right we find the characteristics of this 'normal' sexuality.

Access to the symbolic dimension of interactions – by studying the social representations of caregivers – is relevant for understanding the issues of professional practices and identity issues. Knowledge of the symbolic processes at work in the practices provides access to the logics of the practices, which can take the form of the prohibition and control of the sexuality of the disabled person; and which can also give meaning to the identity questions of the caregivers provoked through their involvement in the sexuality of people with the disease (Apostolidis & Dany, 2014; Dany & Di Tucci, 2019).

CONCLUSION

We hope, through this contribution, to have contributed to a reflection on the place and the role of the socio-representational dimensions that inform thinking on ‘normal’ and ‘disabled’ sexuality. The common-sense theories, such as social representations theory, constitute a ‘base’ on which individuals and societies rely to give meaning to situations while drawing the contours of related social practices and their legitimacies. They allow us to explain the world and build *regimes of truth* for daily explanation. Work on the content of representations makes it possible to consider the representations and other pre-existing theories of the subjects, and to study their role as socio-cognitive filters – that is to say as systems for receiving, decoding and interpreting information from social reality (cf. Apostolidis & Dany, 2012a, 2012b). This work on representational content makes it possible to unveil the dynamic impact of the social on cognitive functioning, as a system of registration and as a system of relationships (e.g., sociogenesis of content and cultural context; updating of content in relational contexts).

‘Disabled sexuality’ holds up a mirror to ‘normal sexuality’ and questions its presuppositions and legitimacy. The problem with ‘disabled sexuality’ is that it constitutes an exacerbated transposition of the way our contemporary societies allow themselves to think about ‘normal’ sexuality or to problematize sexual behaviour. To summarize broadly some of the contributions of this psychosocial reflection on the encounter between sexuality and disability, it seems important to us to underline the fact that ‘disabled sexuality’ does not exist as an autonomous object. ‘Disabled sexuality’ constitutes a mirror of ‘normal sexuality’. In this sense, ‘normal sexuality’ remains the general interpretive framework, and finally, ‘disabled sexuality’ is an exacerbated transposition of how our societies think about ‘normal sexuality’ and disability.

Through this contribution, we wished to call into question our ‘evidence’. The study of social representations turns out to be a particularly heuristic tool from this perspective. The various elements presented point to the mainly conflictual dimension that ‘disabled sexuality’ brings to the societal project of the social participation and inclusion of disabled people. This conflict is based, for example, on the limitation that can be underlined, with regards to the need to distinguish public and private spheres (sexuality falling within the private and intimate sphere). Furthermore, sexuality is a ‘separate’ human activity; it is the subject of particularly significant normative issues in all societies. Caring for the sexuality of people with disabilities is marked by ideological issues tinged with social values. The study of social representations sheds light on some of these issues.

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